17. Appendices

17.1 Staging of lung cancer

Stage of disease at diagnosis in Cancer Registry of Norway (1)

The stages used in survival analyses are as follows:

Localized: An invasive neoplasm confined entirely to the organ of origin

Regional: The neoplasm has extended beyond the limits of the organ of origin into

regional lymph nodes (clinical or histological) or directly into surrounding

tissue or organs

Distant: The neoplasm has spread to other lymph nodes, metastasized to remote organs

(liver, lung, brain, skin, bone system a.o.)

Unstaged: Information either unknown or insufficient to assign a stage

TNM Descriptors in the International System of Staging Lung Cancer (82)

Primary tumor (T)

TX Primary tumor cannot be assessed, or tumor proven by the presence of

malignant cells in sputum or bronchial washings but not visualized by imaging

or bronchoscopy

TO No evidence of primary tumor

Tis Carcinoma in situ

Tl Tumor <3 cm in greatest dimension, surrounded by lung or visceral pleura,

without bronchoscopic evidence of invasion more proximal than the lobar

bronchus* (ie, not in the main bronchus)

Tumor with any of the following features of size or extent:>3 cm in greatest

dimension, involves main bronchus, >2 cm distal to the carina, invades the visceral pleura. Associated with atelectasis or obstructive pneumonitis that

extends to the hilar region, but does not involve the entire lung.

Tumor of any size that directly invades any of the following: chest wall

(including superior sulcus tumors), diaphragm, mediastinal pleura, parietal pericardium; or tumor in the main bronchus <2 cm distal to the carina, but without involvement of the carina; or associated at electasis or obstructive

pneumonitis of the entire lung

Tumor of any size that invades any of the following: mediastinum, heart, great vessels, trachea, esophagus, vertebral body, carina; or tumor with a malignant pleural or pericardial effusion, or with satellite tumor nodule(s) within the ipsilateral primary-tumor lobe of the lung

Regional lymph nodes (N)

NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
NI	Metastasis to ipsilateral peribronchial and/or ipsilateral hilar lymph nodes, and intrapulmonary7 nodes involved by direct extension of the primary7 tumor
N2	Metastasis to ipsilateral mediastinal and/or subcarinal lymph node(s)
N3	Metastasis to contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene, or supraclavicular lymph node(s)

Distant metastasis (M)

MX Presence of distant metastasis cannot be assessed

MO No distant metastasis

Ml Distant metastasis present

Most pleural effusions associated with lung cancer are due to tumor. However, there are a few patients in whom multiple cytopathologic examinations of pleural fluid show no tumor. In these cases, the fluid is nonbloody and is not an exudate. When these elements and clinical judgment dictate that the effusion is not related to the tumor, the effusion should be excluded as a staging element and the patient's disease should be staged Tl, T2, or T3. Pericardial effusion is classified according to the same rules.

*Separate metastatic tumor nodule(s) in the ipsilateral nonprimary-tumor lobe(s) of the lung also are classified Ml.

Stage	TNM Subset
0	Carcinoma in situ
IA	T1N0M0
IB	T2N0M0
IIA	T1N1M0

^{*}The uncommon superficial tumor of any size with its invasive component limited to the bronchial wall, which may extend proximal to the main bronchus, is also classified Tl.

IIB	T2N1M0 T3N0M0
IIIA	T3N1M0 T1N2M0 T2N2M0 T3N2M0
IIIB	T4N0M0 T4N1M0 T4N2M0 T1N3M0 T2N3M0 T3N3M0 T4N3M0

IV Any T Any N Ml

Sources:

- 1. Hansen S LE, Norstein J, Næss Å. Cancer in Norway 2000. Oslo: Cancer Registry of Norway. Institute of Population-based Cancer Research, Oslo Norway; 2002.
- 2. Mountain CF. Revisions in the International System for Staging Lung Cancer. Chest. 1997 Jun;111(6):1710-7.

^{*}Staging is not relevant for occult carcinoma, designated TXNOMO.

17.2 Performance status scale according to WHO

- 0. Able to carry out all normal activity without restriction
- 1. Restricted in physical tre
- 2. nous activity bur ambulatory and able to carry out light work
- 3. Ambulatory and capable of all self-care bur unable to carry out any work, up and about more than 50% of waking hours
- Capable of only limited self-care, confined to bed or chair more than 50% of walking hours
- 5. Completely disabled, cannot carry on any self-care, totally confined to bed or chair

Source:

WHO handbook for reporting results of cancer treatment. Geneva, Switzerland: World Health Organization, 1979; Publication No. 48 (83)

17.3 Questionnaire to chest physicians (translated from Norwegian)

-									
Questionnaire a	mong lung specialists	and d	locto	rs in	train	ing iı	n lun	g	
medicine									
Name of the									
doctor									
Age									
Gender									
How many years									
training in a lung									
department?									
_	The Cancer Registry	5%	10	20	30	40	50	75	100
	has quality indicators		%	%	%	%	%	%	%
	for lung cancer with								
	following results								
Patients with	11 %								
unknown stage									
Patients with	9 %								
unknown									
histology									
Patients with	16 %								
surgical resection									
Patients with one	30 %								
year survival									

Which deviation in percentage in your patient population would make you to change your own routines?

Please mark in the table for every indicator!

Thank you!

Knut Skaug Amund Gulsvik

17.4 Spørreskjema til lungespesialister

Spørreskjema bl	lant lungespesialister o	g leg	er i ı	ıtdan	nelse	i luı	ngem	edisi	n
Navn på lege									
Alder									
Kjønn									
Hvor mange år ved lungeavdeling/- seksjon?									
	Kreftregisteret har kvalitetsindikatorer for lungekreft med følgende resultater	5%	10 %	20 %	30 %	40 %	50 %	75 %	100 %
Pasienter med ukjent stadium	11 %								
Pasienter med ukjent histologi	9 %								
Pasienter med kirurgisk reseksjon	16 %								
Pasienter med ett års overlevelse	30 %								

Hvilke avvik i *prosentpoeng* i din pasientpopulasjon vil få deg til å forandre egne rutiner?

Vennligst kryss av i tabellen for hver indikator.

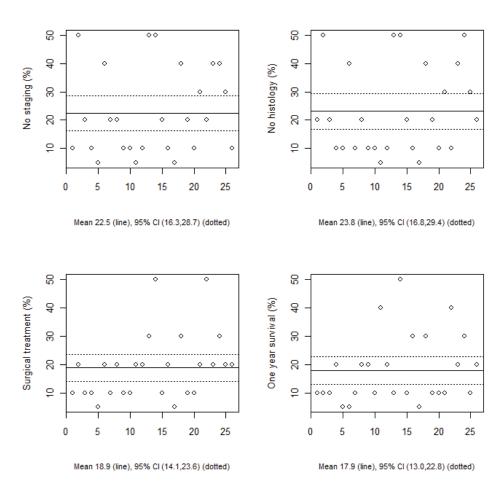
Takk for hjelpen!

Knut Skaug

Amund Gulsvik

17.5 Svar på spørreundersøkelse hos lungeleger

Supplementary figure 2. Relative percentages deviation (minimal important difference) from the national average on four quality indicators sufficient to change the management of lung cancer. Answers given by 26 physicians at the Department of Thoracic Medicine, University of Bergen. The x axes denote physicians by number 1-26.



CI = Confidence interval.

17.6 Case record form (CRF, Translated from Norwegian)

CASE RECORD FORM FOR PATIENTS WITH LUNG CANCER AT HAUGALANDET Cancer in lungs (162), pleura (163) and mediastinum (164) in the hospital district to Haugesund Hospital 1,1,90-31,12,94 Date of recording: Patient number: National identity number (11 digits) Codes: Age at time of diagnosis Gender: Male Female ☐ Skaug (Number of years: The age in years when diagnosis was made) Fluge Others In which municipality was/is the patient living: ☐ Etne Sveio Haugesund ☐ Tysvær Sauda □ Bokn □ Ølen ■ Suldal ☐ Vindafjord Utsira Other Who referred the patient to the hospital? ☐ Referred direct from the primary health care ☐ Referred from preventive health care (Norwegian population Survey, health controls) Referred from other hospitals and health institutions Referred from other specialists (ENT, radiologists and surgeons) ☐ Direct contact from patient to lung specialist at the hospital ■ Unknown Number of admissions at Haugesund hospital (from start of the actual disease) Date of admission 2. admission 7. admission Total number of hospital days for >10 admissions Number of admissions at Haukeland University Hospital Number of admissions at other hospitals Date of diagnosis (the date when histological or cytological diagnosis was made) Start of the disease (When started the symptoms, or when was a chest X-ray taken when no symptoms) Still alive ☐ Yes ☐ No Date of death: Report sent to Cancer registry of ☐ Yes ☐ No Norway Date: Comorbidity (at the time of diagnosis) OLS (ICD 490-496) ☐ Yes ☐ No Other diseases Cardiac disease (ICD 410-429) ☐ Yes ☐ No ICD-9

Page 1

CASE RECORD FORM FOR PATIENTS WITH LUNG CANCER AT HAUGALANDET Cancer in lungs (162), pleura (163) and mediastinum (164) in the hospital district to Haugesund Hospital 1,1,90-31,12,94 National identity number: Patient number: (11 digits) Symptoms given in the Haugesund hospital record which caused the contact with the hospital: A. From lungs/airways B. Symptoms from organs outside Yes No Yes No Cough Weight loss (more than 3kg in 6 months) Dyspnoea Reduced general condition Hemopthysis Head ache Chest pain Nausea Repeated pneumonias Paresis or paresthesia Hoarseness with paresis of the vocal cord Skeletal pain $\overline{\Box}$ Paresis of diaphragm Personality changes Vena cava superior syndrome Other symptoms Other symptoms from lungs/airways Occupational history (from patients' records) Occupational history is absent (in the all patient records) ☐ Occupational history is bad (one occupation, no information about time) Occupational history is good (more occupations with time and duration) □ Occupational history is very good (from end of school until the present disease) Occupational exposure (from patients' records) Exposed to asbest □ yes □ no Other carcinogens □ yes □ no No specific occupational exposure □ yes □ no Tobacco history (grade from no information to very good, which gives the total exposure in number of pack years) ☐ Tobacco history is absent □ Tobacco history is bad ☐ Tobacco history is good (gives information about quantity and duration) □ Tobacco history is very good (gives information about total exposure) Tobacco consumption □ Unknown □ Daily smoker ■ Not daily smoker Former smoker ■ Never smoker Pack years (number - in daily smokers and former smokers) (unknown: 99) Clinical findings No Yes Palpable supraclaviculary glands Hepatomegaly Vena cava superior syndrome

□1 □2 □3 □4 □ unknown

 \square 0

Focal neurological signs

Performance status (WHO)

CASE RECORD FORM FOR PATIENTS WITH LUNG CANCER AT HAUGALANDET

Cancer in lungs (162), pleura (163) and mediastinum (164) in the hospital district to Haugesund Hospital 1,1,90-31,12,94 Patient National identity number: number: (11 digits) Laboratory tests: Hemoglobin g/dl (unknown: 99,9) (number) Yes No Unknown Elevatet ASAT A. FEVI (liters, if unknown 9.99 Elevatet ALAT Elevated ALP B, FEVI (% of predicted, if Elevated GGT unknown 99,9) Spirometry taken П \Box X-ray of tumour at the time of diagnosis Is description present □ yes □ no Location ☐ Left lung ☐ Right lung ☐ Both lungs ☐ Not visible Largest diameter (cm): (missing: 99) CT thorax: Done □ yes □ no Surgical resection possible Bronchoscopy: Done □ yes □ no Central tumour (visible by bronchoscopy) ☐ yes ☐ no Peripheral tumour (not visible) □ yes □ no Skaug Bronchoscopist □ Others Main localization (by visible tumour in bronchopy) □ Trachea ☐ Right main bronchus ■ Left main bronshus ☐ Right stem bronchus □ Left upper lobe ☐ Right upper lobe Left lingual ☐ Right median lobe □ Left lower lobe ☐ Right lower lobe □ Unknown Tissue diagnostic sampling Result of tissue diagnostic sampling Diagnosis Diagnosis not Procedure Not done obtained obtained Biopsy when visible tumor Transbronchial fine needle aspiration Brush Bronchial aspiration Transbronchial biopsy when no visible tumour CT-guided biopsy Pleural fluid Pleural biopsy Biopsy of other organs

Expectorate

CASE RECORD FOR Cancer in lungs (162), pleura (
National identity number: (11 digits)].		100	Patient Imber:
Diagnosis ☐ Small cell lung cancer ☐ Adenocarcinoma ☐ Squamous cell carcino ☐ Undifferentiated, non-	ma		enosquamous ca cnoid tumour ner	rcinoma	
TNM-classification T1					
Staging					
TNM-group	Stage				
T1N0M0	□IA				
T2N0M0	□IB				
T1N1M0	□IIA				
T2N1M0	T. Digwey				
T3N0M0	□IIB				
T3N1M0					
T1-T3N2M0	IIIA				
T4N0-N2M0					
T1-T4N3M0	□ IIIB				
All T, All N, M1	□IV				
Treatment					
A. Surgery	☐ Exploratory	surgery	Resection		No surgery
If resection:	□ Lobectomy		□ Bilobectom	y □F	ulmectomy
Surgically considered cur	ed: yes	□no	☐ Unknown		
B. Chemotherapy ACO (adriamycin, cyclor Cisplatin/Vepecid Number of courses Dose adjustment during of		in)	☐ yes ☐ yes ☐ yes ☐ yes ☐ < 5 courses ☐ yes	no no no 5 courses	s □> 5 courses
1					
C. Radiation					
Only treatment	Additional to cheme	otherapy	☐ Additional (to surgery	☐ No radiation
D. Resection, chemother	rapy, or radiation		□ yes	□ no	

CASE RECORD FORM FOR PATIENTS WITH LUNG CANCER AT HAUGALANDET Cancer in lungs (162), pleura (163) and mediastinum (164) in the hospital district to Haugesund Hospital 1,1,90-31,12,94 National identity number: Patient number: (11 digits) Place of death died in hospital died in nursery home or other institution not known died at home Number of A. Symptoms in the terminal stage (noticed in the hospital record the last two months) □ yes □ no weeks treated (unknown: 99) B. Pain ■ No pain 1. Pain with no treatment ☐ Treated with peripheral analgetics ☐ Treated with opiates □ Treated with opiates via pain infuser Other analgetic measures □ ves □ no C. Dyspnoea ☐ Caused of central obstruction ☐ Caused of pleural fluid Other causes □ No dyspnœa D. Nausea ☐ Present, but not treated □ Treated pharmacologically ☐ No nausea E. Cough ☐ Present, but not treated ☐ Treated pharmacologically ☐ No cough F. Hemopthysis ☐ Present, but not treated ☐ Needed treatment ■ No hemopthysis G. Anxiety/depression ☐ Treated pharmacologically ☐ No anxiety/depression ☐ Present, but not treated Treated with diazepam ☐ yes ☐ no yes no Treated with or hypnotics or other anxiolytic treatment Treated with andidepressive medication H. Neurological signs □ Dizzyness or headache Duration number of weeks □ Paresis or other neurological symptoms □ No neurological signs I, Reduced general condition (the second last month alive) According to the description of WHO 0 1 2 □3 □4 unknown Related to the Cancer Registry of Norway Recorded in the Cancer Registry of Norway □ yes □ no □yes □ no Recorded in the hospital records of Haugesund Hospital

17.7 Registreringsskjema

ixtert tranger (102)	, pleura (163) og	mediasem	and (201) 1 03				.12.94
	1					Г	
Registreringsdat	0		· <u> </u>	Ш_	9000000	Pasientnr.	
Fødselsnr. (11 sit	fer)						Kod
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	10						□ An
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	□ Tysvær □ Vindafjord	☐ Saud			□ Andre		
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Hvem henviste p							
☐ Henvist direkte f							
☐ Henvist fra foreb				ndersøkeise, helsel	kontroll-u.s.)		
☐ Henvist fra andre				200			
☐ Henvist fra andre		_	_				
☐ Direkte kontakt a	v pasient til lun	gespesiali	ist på sykehu	set			
☐ Ukjent							
Antall sykehusop	phold ved FIF	I (fra start	t av aktuell s	ykdom)			
Innleggelsesdato			Liggedag	er			Ligged
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2. opphold		+	1 1	7. opphold	H	-11-1-1	
3. opphold				8, opphold			
4. opphold				9. opphold			
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5. opphold	. سا			10. opphol	a L.L.	اللاا.	ш
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Antall opphold v	d Haukeland	Sykehus		4			
Antall opphold ve	ed andre sykel	ius	19				
Diagnosedato (Da	to da cytologisk el	ler histolog	gisk diagnose	ble stilt)			
	år startet symptor	ner, eller n	år ble det tatt	rontgenbilde			
Sykdomsdebut (N							
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Sykdomsdebut (N av toraks uten sympto		□ia	□ nei	Dødsdato			
Sykdomsdebut (N av toraks uten sympto	WES	□ja	□ nei	Dødsdato	H-H	=:==	
Sykdomsdebut (N		□ ja □ ja	□ nei	Dødsdato Dato			
Sykdomsdebut (N av toraks uten sympto Lever fortsatt Melding sendt Ki	eftregisteret	□ja].	
Sykdomsdebut (N av toraks uten sympto Lever fortsatt	eftregisteret	□ja]. -	

Hoste	Fødselsnr. (11 siffer)		Pasientnr.	
Hoste	Symptomer angitt i FIH journa	al som var for:	anledning til sykehuskontakt	
Brystsmerter	Hoste	Ja Nei	Vekttap (mer enn 3 kg på 6 mnd)	Ja
□ Yrkesanamnesen mangler (i hele journalen) □ Yrkesanamnesen er dårlig (ett yrke uten tidsangivelse) □ Yrkesanamnesen er bra (evt. flere yrker med tidsangivelse) □ Yrkesanamnesen er meget god (fra slutten av skolen til akt. sykdom) Yrkeseksposisjon (journalopplysninger) Eksponert for asbest □ ja □ nei Andre carcinogener □ ja □ nei Ingen spesiell yrkeseksposisjon □ ja □ nei Tobakksanamnese (Graderes fra ingen opplysninger til meget god, som gir total eksposisjon i antall pakke år) □ Røykeanamnesen mangler □ Røykeanamnesen er dårlig □ Røykeanamnesen er bra (gir opplysning om mengde eller varighet) □ Røykeanamnesen er meget bra (gir opplysning om total eksposisjon) Tobakksforbruk (på diagnosetidspunkt minus to måneder) □ Ukjent □ Daglig røyker □ Ikke daglig røyker □ Tidligere røyker □ Aldri røyker Pakke år (antall - hos daglige røykere og tidligere røykere) □ (ukjent 99) Kliniske funn Ja Nei Palpable supraclav. lymfekn. □ Hepatomegali Vena cava superior syndrom □	Brystsmerter Recidiv pneumonier Heshet med stemmebåndsparese Diafragmeparese Vena cava superior syndrom		Kvalme Pareser eller parestesier Skjelettsmerter Personlighetsforandringer	
Yrkeseksposisjon (journalopplysninger) Eksponert for asbest	□ Yrkesanamnesen mangler (i hele □ Yrkesanamnesen er dårlig (ett yr □ Yrkesanamnesen er bra (evt. fler	journalen) ke uten tidsangi e yrker med tids	angivelse)	
□ Røykeanamnesen er dårlig □ Røykeanamnesen er bra (gir opplysning om mengde eller varighet) □ Røykeanamnesen er bra (gir opplysning om total eksposisjon) Tobakksforbruk (på diagnosetidspunkt minus to måneder) □ Ukjent □ Daglig røyker □ Ikke daglig røyker □ Tidligere røyker □ Aldri røyker Pakke år (antall - hos daglige røykere og tidligere røykere) Kliniske funn Ja Nei Palpable supraclav. lymfekn. □ □ Hepatomegali □ □ Vena cava superior syndrom □ □	Eksponert for asbest Andre carcinogener	□ja □nei □ja □nei		
Tobakksforbruk (på diagnosetidspunkt minus to måneder) Ukjent Daglig røyker Ikke daglig røyker Tidligere røyker Pakke år (antall - hos daglige røykere og tidligere røykere) Kliniske funn Ja Nei Palpable supraclav. lymfekn. Hepatomegali Vena cava superior syndrom	□ Røykeanamnesen mangler □ Røykeanamnesen er dårlig □ Røykeanamnesen er bra (gir opp	lysning om men	gde eller varighet)	
Kliniske funn Ja Nei Palpable supraclav. lymfekn.	Tobakksforbruk (på diagnosetidsp ☐ Ukjent ☐ Daglig røyker ☐	unkt minus to må Ikke daglig røyl	neder) ker 🗆 Tidligere røyker 🗀 Aldri røyker	
	Kliniske funn Palpable supraclav: lymfekn, Hepatomegali		crc) [] (ukjent 99)	

Fødselsnr. (11 siffer)		Pasientnr.
Laboratorieprøver		
Hemoglobin g/dl (tallverdi)		(ukjent 99,9)
Forhøyet ASAT	Ja Nei Ukjent	
Forhøyet ALAT		A. FEV1 (liter, hvis ukjent 9,99)
Forhøyet ALP		P. FEIM of C.
Forhøyet GGT		B. FEV1 (% av forventet, hvis ukjent 99,9)
Spirometri tatt	□ja □ nei	
Røntgen av svulsten på	diagnosetidspunk	ttet
Foreligger beskrivelse	□ja □nei	
Lokalisasjon	☐ Venstre lunge	☐ Høyre lunge ☐ Begge lunger ☐ Ikke synbar
Største diameter (cm)	(mangl	er 99)
CT toraks: Utført		□ ja □ nei
Operabel (K. Skaugs vui	rdering)	□ ja □ nei □ ikke mulig å vurdere
Bronkoskopi: Utført		□ ja □ nei
Sentral tumor (bronkosk	opisk tegn til tumo	r) 🗆 ja 🗆 nei
Perifer tumor (ikke synli	g tumor)	□ ja □ nei
Bronkoskopør		☐ Skaug ☐ andre
Hovedlokalisasjon (ved	bronkoskopisk sy	valig tumor)
☐ Trakea		
☐ Høyre hovedbronkus		☐ Venstre hovedbronkus
☐ Høyre stammebronkus		☐ Venstre overlapp
☐ Høyre overlapp		□ Venstre lingula
☐ Høyre midtlapp		☐ Venstre underlapp
☐ Høyre underlapp		☐ Ukjent
Vevsdiagnostikk Prosedyre		Resultat av vevsdiagnostikk Diagnostisk Dike diagnostisk Bike utført
Biopsi ved bronkoskopis	k synlig tumor	
Transbronkial finnål	S 573	
Børste		
Bronkial aspirat		
Transbronkial biopsi ute	n synlig tumor	
CT-veiledet biopsi		
Pleuravæske		
Pleurabiopsi		
Biopsi av andre organer		

		ER MED LUNGEKREFT PÅ HAUG i sykehusområdet til Fylkessjukehuset i Hau	
Fødselsnr. (11 siffer)			Pasientnr.
Diagnose .			
☐ Småcellet anaplastisk o	carcinom	☐ Adenoskvamøst carcinom	
☐ Adenocarcinom		☐ Carcinoid tumor	83
☐ Plateepitelcarcinom		☐ Annet	
☐ Lite diff., ikke småcelle	et carcinom	☐ Ingen vevsdiagnose	
TNM-klassifikasjon			
OTI OT2 OT3	□T4 □TX		
□ N0 □ N1 □ N2	□N3 □NX		
□ M0 □ M1 □ MX			
Stadieinndeling			
TNM-gruppe	Stadium		
T1N0M0	□ IA		
T2N0M0	□IB		
T1N1M0	□ IIA		
T2N1M0	□ ПВ		
T3N0M0 _	LIID		
T3N1M0	□ IIIA		
T1-T3N2M0	u ma		
T4N0-N2M0	□ IIIB		
T1-T4N3M0 _	L IIID		
Alle T Alle N M I	□IV		
Behandling			
A. Kirurgi	☐ Eksplorativ kirurgi	☐ Reseksjon ☐ Ingen kirurgi	
Hvis reseksjon:	37. St.	obektomi 🗆 Pulmectomi	
Kir. vurdert kurativ	□ja □nei □ukje	ent	
202 12			
B. Cytostatika	□ ja □ nei		
ACO-kur	□ja □nei		
Cisplatin/Vepecid	□ ja □ nei	en communicate accessor	
Antall kurer	□ <5 kurer □ 5 kure		
Doseendring under cyto	ostatikabehandling	a □ nei	
C. Bestråling		8	
☐ Eneste behandling	☐ Tilleggsbehandling til c	ytostatika 🛘 Tilleggsbehandling til kir	urgi 🛘 🗆 Ingen bestråling
D. Reseksjon, cellegift	eller bestråling 🗆 j	a □ nei	
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Til stede, men ikke	behandlet	☐ Behandl	ngstreng	ende	☐ Ingen hen	nopthyse		
. Angst/depresjon								
Til stede, men ikke	behandlet	☐ Behandl	et medika	mentelt	☐ Ingen ang	st/depr.		
Behandlet med ber	zodiazepin	derivater	□ja	□ nei				
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Nedsatt almentilst			10					
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